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Research Article

How Can the Arts Influence the Attitudes of Dementia Caregivers? A Mixed-Methods Longitudinal Investigation

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Abstract

Background and Objectives: Arts activities can improve social connectedness and foster reciprocity between people living with dementia and their caregivers. The extent to which the arts can help shape attitudes towards dementia remains unclear. This paper explores the impact of a 12-week visual arts program “Dementia and Imagination” on the attitudes of family and professional caregivers through a mixed-methods longitudinal investigation, underpinned by a conceptual framework of the arts in dementia care.

Research Design and Methods: One hundred and forty-six family and professional caregivers were recruited across three settings in England and Wales (residential care homes, a county hospital, and community venues). Quantitative and qualitative data on caregivers’ attitudes and perceptions of the impact of the arts program were collected through interviews at three time points.

Results: Thematic analysis identified four themes shared across the caregivers: (1) *Recognizing capabilities*, (2) *Social connectedness*, (3) *Improvements to well-being*, and (4) *Equality and personhood*. Two further themes were distinct to family caregivers: (5) *Duration of the effects of the art program*, and (6) *Enriched perspective*. The final theme *Inspiring professional development* was distinct to the professional caregivers. The quantitative analysis found no effect for caregivers’ attitude change over time. Family caregivers scored significantly lower than professional caregivers at each of the three time points.

Discussion and Implications: Art programs have the potential to make visible the capabilities of the people living with dementia, enabling caregivers to see the person behind the condition. This study highlights practice implications for future implementation, such as the role of the arts in dementia care education.

Keywords: Dementia, Art, Intervention, Caregivers, Attitudes, Mixed-methods, Longitudinal, Qualitative

Recognizing dementia as a global public health priority, the World Health Organization (WHO) (2017) directs an area of action toward improving societal understandings of living with the condition. This is in response to the narrow and negative way of thinking about dementia that is pervasive in society (e.g., McManus & Devine, 2011), which leads to stigma and social exclusion (WHO, 2017). An emerging area

of interest for challenging and improving negative perceptions of dementia is engagement in the arts. In this study, we undertake a longitudinal exploration of the perceptions of dementia of family and professional caregivers whose family members or clients took part in a 12-week-visual arts program.

We focus on the perceptions of caregivers for two reasons. First, caregivers’ views about dementia can influence their

understanding of the behaviors they are observing; for example, they might understand a “challenging behavior” in terms of characteristics of the person, rather than an aspect of the condition (Quinn, Jones, & Clare, 2017). These views can then influence how they might respond to the person. Second, caring for a person living with dementia is regularly associated with a negative impact on physical and mental health (Gilhooly et al., 2016). Therefore, initiatives that enable person-centered care (e.g., the arts) and help caregivers see the person behind the condition are important for the delivery of high-quality caring experiences.

Conceptual Framework—Art Programs in Dementia Care

The arts potentially provide different ways to understand dementia, enable person-centered approaches to care, and bring about benefits for those involved. The conceptual framework underpinning this study was derived from a realist review of primary research of art programs for people living with dementia, and a qualitative exploration of stakeholder perspectives of art programs (Figure 1). These sources were synthesized alongside broader theory to understand what works, for whom, how, why, and in what circumstances (Windle, Gregory, et al., 2018). These suggested effective programs were achieved through essential attributes of two key conditions (a provocative and stimulating aesthetic experience; dynamic and responsive artistic practice) that could underpin effective programs in any given

setting. These conditions were important for a number of cognitive, social, and psychological responses, which led to improvements in well-being, cognitive processes, and social connectedness for people with early to more advanced dementia. There were indications of improved perceptions of dementia within the wider social networks of people living with dementia. The theories of cognitive stimulation, resilience, and person-centered care further explained how and why visual art programs may “work.”

For care professionals working in a residential setting, creative art programs offer a context to engage with residents outside of their normal caring routine. Mechanisms central to facilitating person-centered care, such as broadening existing perceptions of people with dementia and their competencies, developing deeper knowledge of the person and their life history and improved communication strategies, are theorized to be developed through creative arts programs (Broome, Denning, Schneider, & Brooker, 2017). One study, “TimeSlips,” found that care-staff who participated in a group storytelling program had more positive views of residents with dementia and devalued residents less than did the control group staff (Fritsch et al., 2009). Other qualitative studies which included the family caregiver alongside the person living with dementia suggest improvements in social interactions and social connections between the family member and the person living with dementia (e.g., Camic, Tischler, & Pearman, 2014; Flatt et al., 2015).

Beyond the care setting, Gregory and Windle (2013) found that schoolchildren changed their perceptions about

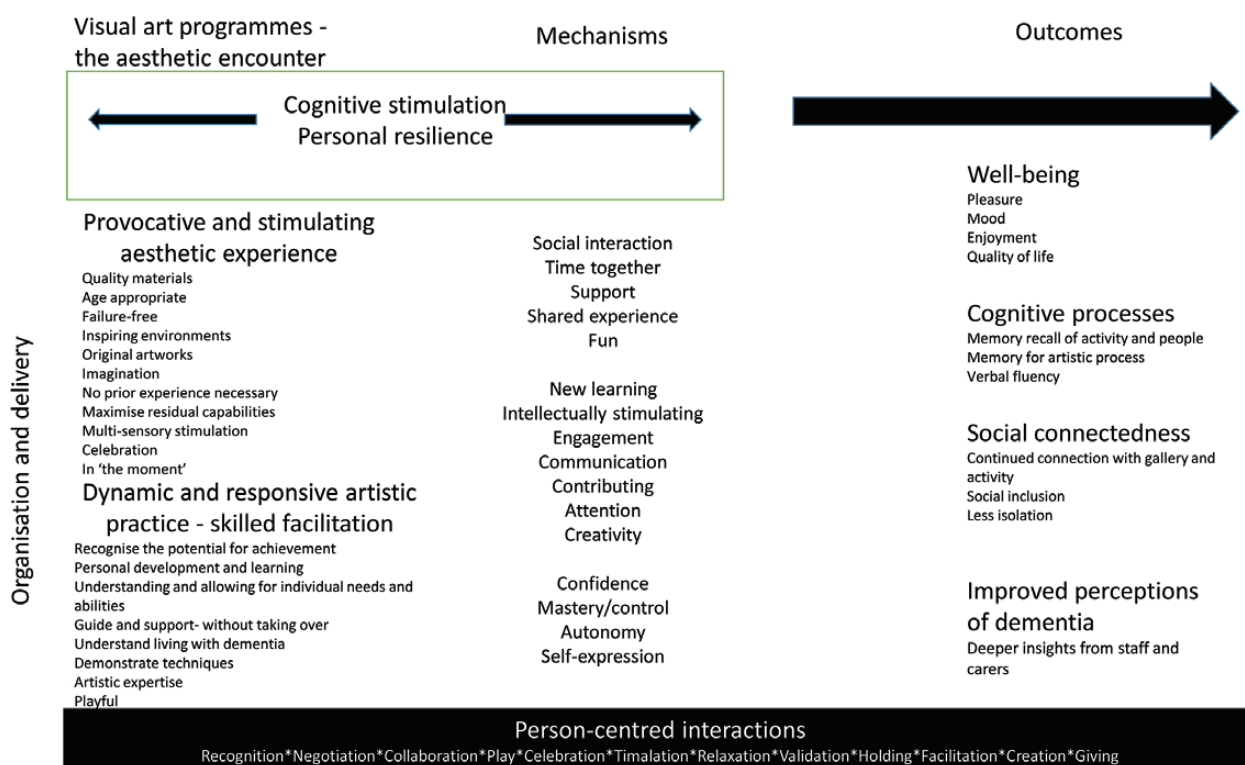


Figure 1. Conceptual framework for art programs in dementia care.

dementia after an art-making session with five people living with the condition. MacPherson, Bird, Anderson, Davis, and Blair (2009) found that despite initial apprehensions, intervention facilitators in a gallery program for people living with dementia developed a deeper insight into dementia and increases in confidence, leading to different perspectives on the condition. Considered together, the literature indicates the arts may enable others to see the person behind the diagnosis and is worthy of further investigation.

Aims of This Research

Our research sought to extend current knowledge by examining the perceptions of a large sample of professional and family caregivers, before and after their care recipient took part in a visual art program. These data were collected contemporaneously with our evaluation of the impact of a visual arts program on people living with dementia (Windle, Joling, et al., 2018). We adopted a pre-post longitudinal mixed-methods design and collected quantitative and qualitative data concurrently to investigate the following questions:

- Does a visual art program designed for people living with dementia lead to changes in caregiver attitudes toward dementia?
- How do the caregivers qualitatively perceive the impact of the arts program?

Methods

Study Design

A mixed-methods longitudinal design with simultaneous data triangulation undertook two types of data collection; a structured questionnaire including validated outcome measures and qualitative, open-ended questions. Professional and family caregivers were recruited between May 2014 and May 2015 alongside the recruitment activity for people living with dementia who took part in the visual arts intervention. The results of the latter research are reported elsewhere (Windle, Joling, et al., 2018), indicating improvements in well-being during art sessions and improved quality of life for the person with dementia, as reported by a caregiver. The peer-reviewed study protocol provides in-depth methodological details (Windle et al., 2016).

Ethics

The study was approved by NHS North Wales research ethics committee—West. All participant information provided was prepared to be simple, clear, and understandable. Bilingual information (Welsh and English) was prepared in Wales.

Setting and Participants

Research Site 1 comprised four residential care facilities in the North East of England. Site 2 was two assessment

units within a National Health Service (NHS) hospital in Derbyshire. Here, the protocol was modified after the second wave of intervention delivery to include recruitment from a day-care service for persons with dementia (PWD). Site 3 involved PWD living in the community in North Wales. For the current analysis, participants were a member of staff in residential care homes or NHS facility, or spouse, family member, or friend of PWD participating in the arts program. Exclusion criteria were a recent or current episode of major mental illness and the inability to communicate verbally through the medium of either English or Welsh.

Recruitment Process

In Site 1, staff were recruited from the participating care homes. In the first instance, the care home manager was asked to assist with recruiting the care home staff. The researchers explained the study to staff when they visited the care home and provided information. In Site 2 NHS staff in a variety of roles in the dementia care services were recruited. The researchers explained the study to staff as part of the units' regular staff meetings, and set up a table with further information about the study. In Site 3, the focus was the spouse/friend/family of the participant with dementia, recruited at the same time as the person with dementia through a number of different approaches. These included primary care (general practices) where a letter of invitation and associated information was sent from the surgery on behalf of the research team to people with a diagnosis of dementia, identified from the practice dementia register. A prepaid response card was enclosed and interested participants were invited to respond via the card, or via telephone or e-mail. In secondary care, NHS memory clinics allowed the researcher to be present and provide study information to patients attending services. The study was also promoted at dementia cafes in the area and through local media.

Study recruitment literature (leaflets, posters, and information sheet) emphasized the voluntary nature of participation. The information provided details of the aims of the study and descriptions of the activities for the participants living with dementia. The information noted the research team's interest in the carers' opinions regarding the impact of creative activities on health and well-being of the person they cared for, and any personal impact on themselves. An appointment was made to return. Participants were allowed sufficient time to consider the information, before the researcher returned to answer any further questions and to gain consent.

Visual Arts Program

The development of the program (Windle, Gregory, et al., 2018) identified the theoretical basis and core content and was adapted into the working principles of the intervention and standardized as the guidelines for intervention delivery. Artists from each regional organization

were expected to deliver the program to four cohorts of people living with dementia of the program in their respective geographical research site (Equal Arts in Newcastle, Nottingham Contemporary in Derbyshire, and Denbigh County Council Community Arts in North Wales); each program was 12 weeks in length, delivered once a week for up to 2 hr per week. The lead artist had prior experience and training in art and dementia and was supported by a second artist. Generally, the sessions were structured so that the first half was an art-viewing activity, followed by art making; however, this was flexible and dependent upon the varying degrees of cognitive impairment in the group. A postintervention review meeting with the artists indicated the program was delivered according to the core principles, and a practitioners' guide, coproduced with the artists, is freely available (Parkinson, Windle, & Taylor, 2017).

Data Collection

Qualitative and quantitative data were collected concurrently through an interview at baseline prior to the start of the 12-week program (Time 1), and follow-up interviews were conducted at 3 months (Time 2) and 6 months (Time 3) later. The Approaches to Dementia Questionnaire (ADQ; Lintern, 2001) is a 19-item scale that assesses a person's attitudes to dementia, originally developed to measure the attitudes of dementia care staff. More recent applications see its use in ascertaining changing attitudes in response to dementia care training (Hattink et al., 2015), and, following minor adaptation, in measuring public attitudes (Cheston, Hancock, & White, 2016), with good internal consistency statistics reported in both studies. The adapted, general population version of the ADQ is used in this study. Scores on the ADQ range from 19 to 95 and higher scores indicate more positive attitudes toward dementia. The measure includes two subscales derived from factor analysis; "recognition of personhood" (11 items to ascertain the extent of person-centered understanding of dementia, e.g., "People with dementia need to feel respected, just like anybody else") and "hope" (8 items to ascertain optimism about the potential and abilities of a person living with dementia, e.g., "Once dementia develops in a person, it is inevitable that they will go downhill"). The extent the participant agrees with the statements are recorded on a five-point Likert scale. Demographic data were obtained at baseline on age (years), gender, marital status, ethnicity, education, occupational status, self-reported health, and proximity to the participant living with dementia.

For the qualitative data, short questions were used to prompt discussion. Interviews explored their experiences, feelings and attitudes, perceived impact of the arts sessions on themselves, and the person living with dementia (e.g., "do you think taking part in the art group will have an effect on your friend/family member/client in your care?"). Follow-up interviews explored the role of time in relation to the impact of the program, and longer-term effects for

both themselves and the person living with dementia (e.g., "do you think taking part in this research will have a lasting effect on you?" "What do you think have been the lasting impressions of the group for your friend/family member/client in your care?"). The extent to which the perceptions of the program influenced changes in practice was specifically explored with the professional caregivers (e.g., has your involvement in the project helped you to recognize any ways of working that you can improve on?).

Data Analysis

Descriptive statistics and frequency distributions were used to describe the characteristics of the study participants. Assumptions of normality were checked by examining the distribution of the residuals of the outcome measures with quantile-quantile plots and histograms. Differences in baseline characteristics between the two types of caregivers were analysed with independent *t* test or chi square depending on the type of variable. Changes over time in the ADQ were analyzed with linear mixed-effects models. The analyses were first conducted on an unadjusted model. The final models were adjusted for baseline characteristics (age, gender, education, and self-rated health).

A random effect was included for the correlation between repeated measurements for the same participant. Caregiver type (informal vs professional) was included as a fixed effect. In addition, models included a fixed effect for time of measurement, the effect of main interest. This was coded as a categorical variable with baseline as the reference category (i.e., time points 1, 2, and 3). We assessed whether any changes in outcomes over time differed between the type of caregiver by testing interaction effects between the time variable and caregiver type. Statistical significance was considered as two-tailed $p < .05$. Data were analyzed in SPSS version 22.

All responses to the qualitative questions were fully transcribed and coded by MC, who had no role in data collection. Utilizing a data-driven, inductive thematic analysis (Braun & Clarke, 2006), the coding was an iterative process, evolving through reading, initial coding, and subsequent rereadings of the data. The researcher (M. Caulfield) developed the initial overarching themes from a table of codes. This was refined by two of the research team (M. Caulfield and G. Windle) at a number of meetings and discussions, through identifying and reviewing subthemes and supporting data extracts. Data interpretation reflects the theoretical model (Figure 1) and is grounded in the participants' perspectives, drawing out differences and similarities.

Results

Sample Characteristics

One hundred and forty-six people met all inclusion criteria and consented to take part in the study and provided

Table 1. Demographic Characteristics of Family and Professional Caregivers at Baseline

	Family (<i>n</i> = 88)		Professionals (<i>n</i> = 58)		By test statistic
Age (mean, <i>SD</i>)	63.3	14.53	46.5	13.93	$t(141) = -6.91, p < .001$
Missing (<i>n</i> , %)	3	3.4	—	—	
Female gender (<i>n</i> , %)	64	72.7	52	89.7	$\chi^2(1) = 5.14, p = .023$
Marital status (<i>n</i> , %)					$\chi^2(4) = 8.19, p = .85$
Married/cohabiting	70	79.6	38	65.5	
Single	6	6.8	9	15.5	
Widowed	3	3.4	3	5.2	
Divorced/separated	8	9.1	8	13.2	
Missing	1	1.1	—	—	
Ethnicity (<i>n</i> , %)					$\chi^2(2) = 2.03, p = .362^*$
White	85	96.5	57	98.3	
Mixed/multiple ethnic	1	1.1	—	—	
Asian/Asian British	1	1.1	—	—	
Missing	1	1.1	1	1.7	
Self-rated health (<i>n</i> , %)					$\chi^2(3) = 10.99, p = .12^*$
Excellent	13	14.8	6	10.3	
Good	37	42	34	58.6	
Fair	16	18.2	8	13.8	
Poor	8	9.1	—	—	
Missing	14	15.9	10	17.2	
Age leaving FT education (mean, <i>SD</i>)	17.12	2.58	17.89	2.69	$t(134) = 1.67, p = .097$
Missing (<i>n</i> , %)	7	8	3	5.2	
Education level (<i>n</i> , %)					$\chi^2(2) = 6.26, p = .044$
Low	21	23.9	5	8.6	
Medium	29	33	27	46.6	
High	37	42	25	43.1	
Missing	1	1.1	1	1.7	
Main activity/occupation (<i>n</i> , %)					$\chi^2(5) = 62.53, p < .001$
Employed/self-employed	28	31.8	53	91.4	
Retired	46	52.3	3	5.2	
Looking after home/family	7	8	—	—	
Long-term sick or disabled	3	3.4	—	—	
Student (full-time)	1	1.1	1	1.7	
Other	1	1.1	—	—	
Missing	2	2.3	1	1.7	
Employment (<i>n</i> , %)					$\chi^2(5) = 7.78, p = .169^*$
Professional	12	13.6	26	44.8	
Managerial/technical	6	6.8	5	8.6	
Skilled (nonmanual)	4	4.5	7	12.1	
Skilled (manual)	3	3.4	12	20.7	
Partly skilled	1	1.1	—	—	
Unskilled	1	1.1	—	—	
Missing	61	69.3	8	13.8	
Proximity to participant (<i>n</i> , %)					$\chi^2(2) = 40.11, p < .001$
Extremely close (main carer on a daily basis)	60	69.8	9	15.5	
Close (work in same ward/home/other family member)	24	27.9	43	74.1	
Not close (met on < 2 occasions)	2	2.3	1	1.7	
Missing	2	2.3	5	8.6	

Note: *Likelihood ratio reported. FT = full time.

demographic data. Long-term follow-up data at 6 months after enrolment were collected from $n = 115$ participants (78.8%). Table 1 presents the baseline sociodemographic

characteristics. The family caregivers were older (mean age = 63) than the care professionals (mean age = 47). “White British” was the most common ethnicity reported by

Table 2. Longitudinal Results for the ADQ and Subscales

	Family caregivers			Professional carers			Total sample			Time estimate*	95% CI	t	df	p
	n	Mean	(SD)	n	Mean	(SD)	n	Mean	(SD)					
ADQ full scale (19–95)														
Baseline	88	73.99	7.7	58	82.88	7.5	146	77.52	8.5					
Time 2: 3 months	72	75.46	8.6	51	82.02	8.0	123	78.18	9.0	0.64	[−0.93; 2.21]	0.8	222.1	.42
Time 3: 6 months	70	74.39	9.0	45	83.03	6.7	115	77.77	9.2	−0.28	[−0.82; 1.24]	−0.4	228.4	.71
Type of caregiver										4.95	[1.70; 8.20]	3.0	203.0	.003
Time × Type of caregiver (T2)										−1.21	[−3.77; 1.34]	−0.9	221.9	.34
Time × Type of caregiver (T3)										0.55	[−1.95; 3.06]	0.43	227.9	.66
Subscale “Hope”														
Baseline	86	25.84	5.1	57	32.36	4.6	143	28.44	5.9					
Time 2: 3 months	73	27.06	4.1	46	31.89	4.6	119	28.93	5.9	0.25	[−0.73; 1.23]	0.50	210.4	.61
Time 3: 6 months	69	26.50	5.8	43	32.58	5.9	112	28.83	5.9	−0.76	[−1.74; 0.21]	−1.54	214.7	.12
Type of caregiver										4.59	[2.00; 7.19]	3.51	90.7	.001
Time × Type of caregiver (T2)										−0.64	[−2.29; 1.00]	−0.77	211.2	.44
Time × Type of caregiver (T3)										0.82	[−0.77; 2.42]	1.0	214.5	.31
Subscale “Personhood”														
Baseline	87	48.22	4.6	56	50.57	4.6	143	49.1	4.7					
Time 2: 3 months	70	48.55	4.6	49	50.16	5.4	119	49.2	5.0	0.46	[−0.64; 1.58]	0.82	213.4	.40
Time 3: 6 months	69	47.91	4.7	44	50.68	4.2	113	48.9	4.7	0.56	[−0.51; 1.64]	1.02	220.9	.30
Type of caregiver										0.01	[−2.21; 2.23]	0.10	110.0	.99
Time × Type of caregiver (T2)										−0.53	[−2.35; 1.29]	−0.57	214.3	.56
Time × Type of caregiver (T3)										0.01	[−2.21; 2.23]	0.00	110.0	.99

Note: *The estimate represents the estimated difference of the scores over time for the total sample, with the baseline score as the reference category. Means are unadjusted. Covariates are education age, gender, and self-rated health.

both family caregivers (96.6%) and professionals (98.3%). Likewise, 72.7% of family caregivers and 89.7% of care professionals were female. Of family members, 69.8% described their relationship to participants as “extremely close,” caring for them on a daily basis. This contrasted with professional caregivers of whom only 15.5% reported the same intensity of relationship with their participant(s). Although 46.6% of family caregivers were retired, 31.8% were still employed or self-employed.

Change in Attitudes to Dementia

The unadjusted model indicated there was no significant change in caregivers’ attitudes to dementia over time ($F[2,234.14] = 0.006, p = .99$). Controlling for age, gender, education, and self-rated health, there was no change over time for the ADQ (Table 2). However, there was a significant main effect for caregiver group ($F[1, 126.82] = 10.76, p < .001$). The mean ADQ scores show that family caregivers were lower for the ADQ at each of the time points compared to the professionals ($T1 = 73.99$ vs 82.88 ; $T2 = 75.46$ vs 82.02 ; $T3 = 74.39$ vs 83.03). The interaction effect between time and caregiver type was nonsignificant ($F[2, 225.48] = 1.06, p = .34$).

Table 2 shows there was no change over time for the ADQ subscale of “hope” and no interaction effect with caregiver group, but a significant main effect for caregiver group ($F[1,66.59] = 14.94, p < .001$). Again, family caregivers had lower mean scores at each of the time points compared to the professionals. There were no differences over time for the whole sample or between caregiver groups for the subscale “recognition of personhood” (Table 2).

Individual Perceptions of the Visual Arts Intervention

Analysis of the data revealed seven themes (Figure 2). Four of these themes were “shared” by both caregiver groups, reflecting their perceptions of the impact of the art program. Of the three themes categorized as “distinct,” two themes reflected the impact on the family or professional caregiver

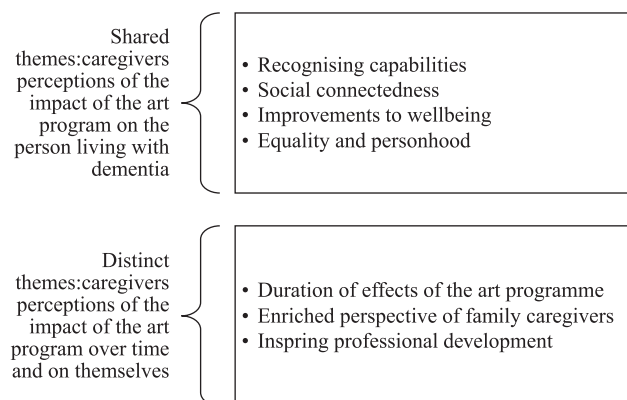


Figure 2. Themes shared by and exclusive to caregiver group(s).

and “duration of effects” captured the uncertainty of the lasting effects of the art program expressed by family caregivers. Quotes are coded as “FC” (family caregivers) and “PC” (professional caregivers).

Shared Themes: Caregivers Perceptions of the Impact of the Art Program on the Person Living With Dementia

Recognizing Capabilities

Both caregiver groups reflected that the art program was a rewarding experience for the person living with dementia, and talked about dementia in terms of what the person could do—their strengths. The art sessions represented a time and place where participants could take the lead in a creative process, “where their interest and preferences are worked with,” which contrasted with much of their daily life governed by routine. The sessions helped revitalize the creative interests of participants:

Gave him a sense of ownership, i.e., his project/event. This being related to the fact that everything else he does apart from weekly walk with friend relies on and involves me. (FC35)

The “sense of achievement” and pride participants felt in their art creations was tangible and described by caregivers as “having effects on their self-worth and self-esteem.” Caregivers recognized the people living with dementia were part of a larger project that created a “a sense of pride about their contributions” (PC26), and that being part of “a group with a purpose” (PC34) enabled them to feel “they belonged to something bigger than them” (PC39), where their efforts contributed to the collective self-esteem and creative outputs.

I think they will recall feeling valued and useful, or at least having a purpose and the ability to achieve that purpose. (PC34)

Social Connectedness

The art sessions facilitated professional and resident interactions, and through the art activities “we became friends, got to know them [residents]” (PC08). One care professional reflected upon “the use of creativity as a framework to have a conversation” (PC06) and through creating art “*everyone ‘glued’ together.*” Another care professional described feeling “like I was part of something special, protected” (PC13).

I think by doing the art you’re talking to each other We all knew that we were meeting up if you know what I mean. It wouldn’t have been the same without the art ... had a specialness about it. (PC13)

The opportunity for participants to engage with others in similar circumstances, with “whom they would not usually interact” (PC22), encouraged friendship. Family caregivers in particular acknowledged the significance of the “social aspect of the art group” (FC45), and the therapeutic

benefits for the person living with dementia of “getting out and meeting people” (FC46) within a supportive environment. For the more cognitively able participants, caregivers saw how talking about their dementia with others who could relate to their experiences helped “them process things in a safe environment” (PC03).

Giving them a shared experience and a chance to share their illness experience without focussing on it can be really helpful. (PC03)

The art program revealed to caregivers the potential isolation that could be experienced for some people living with dementia, and the importance of being able to take part and meet others in a similar situation.

It makes him feel he fits in. “They are all as daft as me” he jokes. Also, he realizes there are some that are worse off and less independent. (FC02)

For family caregivers’ the opportunity to meet others and exchange “practical and emotional support” was important in terms of how they perceived dementia:

One thing I picked up from attending, it is good for people to meet new people, it challenges or reinforces your beliefs, makes you question things. The social part is very very important and to sit with different people was very important. (FC48)

Improvements to Well-Being

Caregivers considered the potential of the art program to “lift [person with dementia] spirit in a meaningful way” (PC03) and contribute to the “enjoyment of life” (FC24) for the person living with dementia. The well-being effects were broad and encompassed participants “feeling more relaxed and connected to each other and to themselves” (PC20). Care professionals noted their clients “seemed more engaged and lively in the arts session than they do in general” (PC05). Caregivers felt that while most of the people living with dementia were not able to recall the specifics of the art activities beyond the end of the sessions, they commented on “an upward spiral of effects” (PC06) that resulted from having attended an art session. People living with dementia often left sessions in a “lovely mood” or were “more chatty the day after the group” (FC10). Consequently, caregivers considered that because participants feel “more settled” this made “caring for her much easier” (FC25).

It’s been very good for him overall I think ... His mood is different, he does things, he gets going and that’s it ... there’s something about it he likes. (FC01)

Caregivers saw how it was possible for the arts sessions to be intellectually challenging and an opportunity for the person living with dementia to “use their imagination” and appreciated that “there was task. He liked that there would be sharing at the end. He didn’t like to go for just dinner” (FC10).

Equality and Personhood

A strength of the art sessions stemmed from their inclusive nature. Family caregivers enjoyed observing the “camaraderie” within the group, in particular how engaged care professionals were in the art sessions and this “enabled everyone to join in the activities on an equal basis” (PC35).

The art project has allowed my granddad to express his likes and dislikes in the project, for example he likes doing the activities but dislikes the loud noises of the music. I feel as though this allowed him to have his voice heard in what he is doing which will have a lasting impression. (FC10)

Caregivers described how people living with dementia were empowered by the independence of “having their own thing” (FC36) and the creative freedom that came from “being able to respond in their own way” (PC35). During the sessions, there was a softening of hierarchy and diffusion of the carer–patient dyad; people living with dementia, caregivers, and the artist facilitators “were there as equals, not carer and cared for” (FC26).

My lasting impressions are how much fun being in the moment and exploring different ideas/arts can have. How it brings people together and creates equality and open-mindedness. (PC26)

The “respect that people were shown as individuals” (PC03) and the fact that the activities were not based “around their diagnosis” (FC27) was liberating for people living with dementia and the caregivers:

She liked being involved in decision making and having her feelings acknowledged. (PC45)

Observing how people living with dementia illustrated their perspectives and emotions supported care professionals in their understanding of them as unique individuals, “in my relationship to my patient ... to see them for who they are” (PC32).

It was just so wonderful to see people like <DD18> and <DD20> brought out of themselves and our staff to really see them as people. That was the main eye opener for me. (PC27)

Distinct Themes: Caregivers’ Perceptions of the Impact of the Art Program Over Time and on Themselves

Duration of the Effects of the Art Program

Family caregivers appeared more cautious in overstating any long-term therapeutic benefits. They were more sensitive to the possibility that their relatives’ capacity to remember the art sessions and to experience long-term well-being effects was dependent on their stage of dementia. Many family caregivers echoed sentiments such as “I think it ‘might’ have calmed him down for an hour or two” (FC19) or “he has

mostly forgotten about it because his dementia has taken a dip" (FC49). Overall, there was a consensus that benefits were "more in the moment" and although "he seems happy when he's there," there is no lasting effect.

Enjoyed the group and the company, I think she has forgotten by the time she comes home. (FC43)

Family caregivers stressed that if the dynamics of the group were not appropriate or activities not suitable this could cause distress and frustration for the person living with dementia because "he couldn't do some of the work at home, which he had hoped he would ... He remembered punching metal in the art group" (FC48).

He enjoyed it whilst he was going but hasn't wanted to join other dementia groups since then, it reminds him of what he's got. [It is] frightening for him and wants to forget his illness and make the most of his life. (FC26)

There was, however, consensus among both family and professional caregivers as to the difficulty in predicting longer-term effects and that "for something to be life changing, it would have to be bigger than one afternoon" (PC07). It was therefore, more likely that people living with dementia took away the sentiment of "shared time with people" rather than, for example, a longer-term change in mood:

Even if they don't remember the visit, they remember the feeling ... It's like when you have a dream and you cannot remember the content but you are left with feeling. (PC07)

Enriched perspective of family caregivers

The art sessions enabled family caregivers to perceive their relative within "a totally different setting" and "experiencing a more vibrant atmosphere" of a creative art group. Some family caregivers expressed surprise at their relative's abilities, and were grateful for the opportunity to "see my mother in a different light ... contributing to the class" (FC34). Even though many benefits were considered "momentary" this did not diminish the value of the art group and encouraged family caregivers to consider other social and creative activities for their relative, e.g., "Our local social worker is collecting us and taking us to singing for the brain" (FC13) or to introduce arts and crafts at home, e.g., "I feel art has become an important part of my husbands' life so I will encourage him for as long as he is able" (FC26).

Crucially, for family caregivers, the art program enabled them to sustain their "loving bond via the activities" and many caregivers were "grateful that we had those sessions, sitting together doing something ... it allowed me to feel he was still there" (PC24). Capturing the moments when their relative was contented and engaged provided tender memories "it gave me some nice memories of my Dad towards the end and that is remarkable" (FC24).

I will take comfort from Dad enjoying something for himself even this late in his life and with Alzheimer's. I will treasure the image he made too. (FC36)

Inspiring Professional Development

The opportunity to observe artists working with their clients "opened staffs' eyes to alternative approaches to arts and crafts" (PC36). Care professionals reported feeling "invigorated by the project," noting the art program "opened all of our eyes on how to mix up an activity" (PC27) and provided "inspiration to research more activities" (PC35). Involvement in the art program built confidence in how to plan activities for residents. Care professionals picked up practical tips such as "make your material relevant," "simple things can have an impact," and "how the use of interesting objects can stimulate discussion" (PC13).

Care professionals reflected how they tend to focus on participants' limitations and at times have a tendency to "rescue them too soon." It was therefore refreshing for them to observe how "the artists didn't see the illness and disability like we do" and to "look past the symptoms a bit more because people surprise you" (PC33). Care professionals appreciated participating in an art program that broadened their knowledge of the role of the arts in dementia care and augmented their understanding of "how much to facilitate ... It is very tricky to set it right and I will remember that" (PC33). The skills and tips they observed they can continue to use and adapt in their own service.

I think it has helped me improve my knowledge about clients with dementia engaging with activities, how it can boost their memories and remind them of their past experiences, also shown me how colour can help them to express their feelings. (PC20)

Discussion

This mixed-methods longitudinal study explored the impact of a visual art-viewing and making program on the attitudes of family and professional caregivers toward dementia. The qualitative exploration revealed themes that were both distinct to and shared by professional and family caregivers. These qualitative findings suggest the art program influenced aspects of the caregivers' perceptions; it made visible the capabilities of the people living with dementia, that the person could still contribute and take part, and enabled caregivers to see the person behind the condition, a fundamental goal of person-centered care (Kitwood, 1997). This empirical finding supports the conceptual framework (Windle, Gregory, et al. 2018). We are unable to say if this ultimately led to improvements in care; however, the professional caregivers described how they learnt some new approaches for their practice. Similarly, family caregivers considered other social and creative activities for their relative following the research.

This additional finding for improvements in dementia knowledge and care adds a new outcome to the conceptual framework.

The qualitative themes appear to reflect the intentions of the ADQ and the subscales of “Hope” and “Personhood,” yet in contrast to the qualitative data, we found no change over time for the ADQ or the subscales of “Hope” and “Personhood” across the total sample, and no change over time for the ADQ or the subscales within either of the caregiver groups. It is difficult to draw firm conclusions about this disparity. One possibility is that the opportunity for caregivers to discuss and express their opinions and thoughts was less rigid compared to the constraints of agreeing or disagreeing with a statement about approaches to dementia care. Another possibility is that the professional caregivers had high scores on the ADQ at the outset of the study, and so were unresponsive to further improvement. In relation to this, there was a significant effect for the type of caregiver, and the family caregivers had lower scores on the ADQ and its subscale “Hope” at each of the time points compared to the professionals.

Few studies have simultaneously examined attitude differences between professional and family caregivers; however, the limited evidence suggests differences exist. The same finding for family caregivers scoring lower on the ADQ than professionals is reported by [Hattink and colleagues \(2015\)](#), who examined the impact of an e-learning program about dementia. They also report the greatest difference in attitudes between caregiver groups was reflected in their sense of “Hope” for the person with dementia at pre (20.48 vs 27.5) and at postintervention (22.33 vs 27.80). However, in contrast to our study, they omitted one of the ADQ questions (“it is important not to become too attached to people with dementia”) because it was deemed inappropriate. On that basis, the improved attitudes in both caregiver groups following their e-learning program are not directly comparable.

Cheston, Hancock, and White’s (2019) survey of dementia attitudes echoes a similar pattern in their data as ours. From a sample of 2,021 individuals, the mean score of those whom were personally affected by dementia and working with people with dementia was higher for total ADQ and the subscales than those personally affected by dementia but not working with people with dementia, and similarly for each of its subscales, with Hope (30.28 vs 27.28) and Recognition of Personhood (47.25 vs 45.61). However, without normative data for comparison, it is difficult to ascertain the true meaning of the distinctions between the two caregiver groups across the different studies.

Strengths and Limitations

The mixed-methods pre–post study design, although rigorously applied, means we cannot draw definitive conclusions about effectiveness of the arts program in relation to attitude change, as there was no randomization or control

comparison group. However, we actively recruited people to a program specifically developed for the purpose of the research, across multiple research sites, and applied eligibility criteria to clearly define the target population. The study also adopted a robust quantitative data analysis strategy. Despite recruitment efforts, the demographic profile of the caregivers was predominantly white British and female. This gendered aspect of caregiving is representative of the demographic characteristics of the broader caregiver population in Europe, where 76% of caregivers were female ([Eurofamcare, 2006](#)). However, further research could usefully focus on the experiences of male caregivers, who may approach the role differently than females. Similarly, understanding the caregiving experiences of black and minority ethnic groups requires future researchers to actively make efforts to ensure inclusion when recruiting.

Participant attrition was reasonable and we had 78.8% complete outcome data for the quantitative outcome measure. Nevertheless, we may have lost access to different qualitative perspectives through attrition. For definitive conclusions of the effectiveness of art programs to change attitudes, further research is required. This could incorporate randomization with a matched comparison/control condition.

Despite its growing application in different populations, the ADQ was not designed specifically in relation to family caregivers. It seeks views regarding people with dementia “in general,” rather than about a specific person with dementia, and the ADQ questions may then be more difficult to answer for a family caregiver who is involved in daily care. Caregivers coresiding with their relative often provide a significant amount of care with limited or no professional support ([Lin, Fee, & Wu, 2012](#); [Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007](#)). They may provide care through obligation rather than choice, have little experience, and often experience emotional, practical, and relational challenges ([Dean, Kellie, & Mould, 2014](#); [Miller-Ott, 2020](#)). In the present study, 69.8% of family caregivers were “extremely close” in proximity to their relative, caring for them on a daily basis, and 80% were cohabiting with the person with dementia, and their responses on the ADQ may reflect difficulties they are encountering in their day-to-day caregiving. Professional caregivers are also susceptible to burnout ([Woodhead, Northrop, & Edelstein, 2016](#)); however, in contrast to family caregivers, they are able to “step away” from the role and are more likely to receive training about dementia. This has implications for practice.

Practice Implications

Despite the qualitative reports, the lower scores on the ADQ for family caregivers in this study and others ([Hattink et al., 2015](#); [Cheston et al., 2019](#)) may indicate an area for further intervention. One implication is that family caregivers could also benefit from training, akin to professional training in scope and content. This could

better prepare them for any changes in relational dynamics and embed knowledge of how to best care for themselves during the process. Caregiver training aimed at raising awareness, improving understanding, and mitigating stigma is recommended by the WHO (2017). This may be particularly important for instilling a sense of “hope” in family caregivers.

The arts may be useful for future caregiver education and training. Elsewhere, there is a growing interest in the development of humanistic aspects of healthcare and how “aesthetic learning” may be important for practical and communication skills, personal development, awareness of self and others, and compassion and empathy (Turton, Williams, Burton, & Williams, 2018). There is little work in dementia education in this new area. Zeilig, Poland, Fox, and Killick (2015) developed the Descartes project, an arts-based approach to dementia care staff development, explored in a care home in England. This proved an engaging educational format for promoting self-reflection and skills recognition, enriching perspectives, and understanding of dementia (Zeilig et al., 2015). More recently, “Creative Conversations” suggests how an art-based program for dementia care staff offered an alternative and creative exploration of dementia, to support the development of compassionate communication and relationship quality; the arts were both a mode for delivering the staff development program and also tools for supporting and understanding communication (Windle et al., 2019). Testing these education and training interventions with family caregivers is worthy of further investigation.

Conclusion

The need to challenge stigma and improve awareness and understanding of dementia is globally acknowledged to meet policy aspirations for dementia-friendly societies and care improvement (Wortmann, 2013). Dementia care is increasingly considering art-based activities for people living with dementia. In the present study, the visual arts program was not able to significantly improve attitudes toward dementia as measured by the ADQ. In contrast, our qualitative findings suggest that well-delivered, professionally led art activities enabled caregivers to understand more about their client or relative; to recognize the capabilities of the person living with dementia; to recognize improvements to their well-being and social connectedness; and improved their own knowledge and understanding of dementia. Although these developments in perspective are subjective, they suggest that opportunities for creativity in the present moment, delivered through an arts session such as the one in this present study, can be useful for enriching understanding of the lived experience of dementia. Arts and cultural organizations, with their wide range of expertise, are ideally situated to deliver such services people living with dementia at all stages of the condition to support the delivery of person-centered care.

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Conflict of Interest

None reported.

References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. doi:10.1191/1478088706qp0630a
- Broome, E., Denning, T., Schneider, J., & Brooker, D. (2017). Care staff and the creative arts: Exploring the context of involving care personnel in arts interventions. *International Psychogeriatrics*, 29, 1979–1991. doi:10.1017/S1041610217001478
- Camic, P. M., Tischler, V., & Pearman, C. H. (2014). Viewing and making art together: A multi-session art-gallery-based intervention for people with dementia and their carers. *Aging & Mental Health*, 18, 161–168. doi:10.1080/13607863.2013.818101
- Cheston, R., Hancock, J., & White, P. (2016). A cross-sectional investigation of public attitudes toward dementia in Bristol and South Gloucestershire using the approaches to dementia questionnaire. *International Psychogeriatrics*, 28, 1717–1724. doi:10.1017/S1041610216000843
- Cheston, R., Hancock, J., & White, P. (2019). Does personal experience of dementia change attitudes? The Bristol and South Gloucestershire survey of dementia attitudes. *Dementia (London, England)*, 18, 2596–2608. doi:10.1177/1471301217752707
- Dean, D., Kellie, J., & Mould, P. (2014). From pushchairs to wheelchairs: Understanding tensions in family decision making through the experiences of adult children caring for ageing parents. *Journal of Marketing Management*, 30, 1703–1721. doi:10.1080/0267257x.2014.934268
- Eurofamcare. (2006). Services for supporting family carers of elderly people in Europe: Characteristics, coverage and usage. <http://www.ukc.de/extern/eurofamcare/documents/>

- Flatt, J. D., Liptak, A., Oakley, M. A., Gogan, J., Varner, T., & Lingler, J. H. (2015). Subjective experiences of an art museum engagement activity for persons with early-stage Alzheimer's disease and their family caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 30, 380–389. doi:10.1177/1533317514549953
- Fritsch, T., Kwak, J., Grant, S., Lang, J., Montgomery, R. R., & Basting, A. D. (2009). Impact of TimeSlips, a creative expression intervention program, on nursing home residents with dementia and their caregivers. *The Gerontologist*, 49, 117–127. doi:10.1093/geront/gnp008
- Gilhooly, K. J., Gilhooly, M. L., Sullivan, M. P., McIntyre, A., Wilson, L., Harding, E.,...Crutch, S. (2016). A meta-review of stress, coping and interventions in dementia and dementia caregiving. *BMC Geriatrics*, 16, 106. doi:10.1186/s12877-016-0280-8
- Gregory, S. A. & Windle, G. (2013). Lost in Art Too...challenging perceptions of dementia. *The Journal of Dementia Care*, 21, 23–25.
- Hattink, B., Meiland, F., van der Roest, H., Kevern, P., Abiuso, F., Bengtsson, J.,...Dröes, R. M. (2015). Web-Based STAR E-Learning course increases empathy and understanding in dementia caregivers: Results from a randomized controlled trial in the Netherlands and the United Kingdom. *Journal of Medical Internet Research*, 17, e241. doi:10.2196/jmir.4025
- Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health*, 1, 13–22. doi:10.1080/13607869757344
- Lin, I. F., Fee, H. R., & Wu, H. S. (2012). Negative and positive caregiving experiences: A closer look at the intersection of gender and relationships. *Family Relations*, 61, 343–358. doi:10.1111/j.1741-3729.2011.00692.x
- Lintern, T. (2001). Quality in dementia care: Evaluating staff attitudes and behaviour (PhD thesis). Bangor, UK: University of Wales.
- MacPherson, S., Bird, M., Anderson, K., Davis, T., & Blair, A. (2009). An art gallery access programme for people with dementia: 'You do it for the moment'. *Aging & Mental Health*, 13, 744–752. doi:10.1080/13607860902918207
- McManus, M., & Devine, P. (2011). *Dementia: Public knowledge and attitudes*. Northern Ireland: Access Research Knowledge (ARK). <https://www.ark.ac.uk/publications/updates/update77.pdf>
- Miller-Ott, A. E. (2020). "Just a heads up, my father has Alzheimer's": Changes in communication and identity of adult children of parents with Alzheimer's disease. *Health Communication*, 35, 119–126. doi:10.1080/10410236.2018.1547676
- Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: Family caregiver burden. *Journal of Advanced Nursing*, 58, 446–457. doi:10.1111/j.1365-2648.2007.04250.x
- Parkinson, C., Windle, G., & Taylor, K. (2017). The dementia and imagination team. Research informed approaches to visual arts programs. <http://www.artsforhealth.org/resources/dementia-and-imagination.pdf>. Accessed February 5, 2017.
- Quinn, C., Jones, I. R., & Clare, L. (2017). Illness representations in caregivers of people with dementia. *Aging & Mental Health*, 21, 553–561. doi:10.1080/13607863.2015.1128882
- Turton, B. M., Williams, S., Burton, C. R., & Williams, L. (2018). Arts-based palliative care training, education and staff development: A scoping review. *Palliative Medicine*, 32, 559–570. doi:10.1177/0269216317712189
- Windle, G., Algar-Skaife, K., Caulfield, M., Zeilig, H., Tischler, V., & Killick, J. (2019). Enhancing communication between dementia care staff and their residents: An arts inspired intervention. *Aging & Mental Health*, 1–10. doi: 10.1080/13607863.2019.1590310 [Epub ahead of print]
- Windle, G., Gregory, S., Howson-Griffiths, T., Newman, A., O'Brien, D., & Goulding, A. (2018). Exploring the theoretical foundations of visual art programmes for people living with dementia. *Dementia (London, England)*, 17, 702–727. doi:10.1177/1471301217726613
- Windle, G., Joling, K. J., Howson-Griffiths, T., Woods, B., Jones, C. H., van de Ven, P. M.,...Parkinson, C. (2018). The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: A mixed-methods longitudinal investigation. *International Psychogeriatrics*, 30, 409–423. doi:10.1017/S1041610217002162
- Windle, G., Newman, A., Burholt, V., Woods, B., O'Brien, D., Baber, M.,...Tischler, V. (2016). Dementia and imagination: A mixed-methods protocol for arts and science research. *BMJ Open*, 6, e011634. doi:10.1136/bmjopen-2016-011634
- Woodhead, E. L., Northrop, L., & Edelstein, B. (2016). Stress, social support, and burnout among long-term care nursing staff. *Journal of Applied Gerontology*, 35, 84–105. doi:10.1177/0733464814542465
- World Health Organization (WHO). (2017). Global action plan on the public health response to dementia 2017–2025. https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/ Accessed January 2018.
- Wortmann, M. (2013). Overcoming the stigma of dementia. *Alzheimer's & Dementia*, 9, P547. doi: 10.1016/j.jalz.2013.04.308
- Zeilig, H., Poland, F., Fox, C., & Killick, J. (2015). The arts in dementia care education: A developmental study. *Journal of Public Mental Health*, 14, 18–23. doi: 10.1108/jpmh-06-2014-0028